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Albinism in India: A Situation Analysis



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Acknowledgement

The writing of this report has been a challenging task as to find out the albinos in the sample states was not that easy. The research team would like to express profound sense of gratitude to Jan Vikas Samiti, Varanasi and its partner organizations for their support in mapping the albinos and data collection.

Research Team

WPRA

Chapter – I

Introduction

Most of the people or communities across the world do not or hardly understand albinism. It is estimated to affect 1 in 17000 all over the world and is mainly caused by a genetic disorder resulting into lack of a pigment, known as melanin, responsible for colour of skin, hair and eyes in human body.

Unfortunately, due to cultural beliefs and the lack of awareness, the condition is surrounded with myths and misconceptions which continue to persist in many parts of the world especially in Sub Saharan African countries where people are predominantly dark skinned. They believe it as a curse or punishment from Gods or ancestors for something wrong done by parents and for centuries children born with albinism have been routinely killed immediately after birth in these countries. In some parts of these countries, albinos are being kidnapped and killed for their blood and bone mainly due to superstitions as they believe that albinos are given super powers.

The word albinism originates from Latin “albus” which means white. In humans, albinism is a rare genetic disorder characterized by complete or partial absence of melanin pigment in skin, hair and eyes due to absence or defect of tyrosinase, a copper-containing enzyme involved in production of melanin. Melanin is the pigment responsible for giving colour to skin, hair and iris of eyes. People with albinism sometimes have vision problems and are hypersensitive to sun rays. For them, exposure to sun rays without some protection may cause skin problems and sometimes lead to skin cancer.

It is reported that Albinism is predominant and common in countries like Sub-Saharan Africa, America, China, India, Japan, Korea. A typical misbelief about Albinism is that it is contagious and most often misinterpreted and handled insensitively due to lack of awareness, cultural beliefs, myths and misconceptions. The level of misinterpretation and exploitation is amplified particularly in countries where the difference in body tone of an Albino has a sharp contrast

with the other community members who are mostly dark skinned (TAF, 2017) Early diagnosis of albinism is most important to manage ocular albinism symptoms which can help in improving general safety and wellbeing, education, self-esteem, and cognitive development among the affected individuals. Albino women and children are more vulnerable according to the UN report as they can face multiple forms of discrimination including ritual kills and physical violence (UN, 2013). The true condition of the life and living of the Albino people came to a highlight when the UN Human Rights Council adopted a resolution in 2013 focusing on prevention of attacks and discrimination against people with Albinism (UN, 2015). Albinos were considered as a specific group of people with particular needs and special attention. On March 26, 2015, the council created the mandate of Independent Expert on the enjoyment of human rights by Albino people. With effect from 2015, the UN announced International Albinism Awareness day on June 13th to promote powerful advocacy for people with Albinism.

In Indian context, an estimated population of albinos is 100 thousand to 200 thousand. They often face social and family discrimination because of their different/ethereal appearance. Due to lack of awareness, most often the condition is misunderstood with Leucoderma or some other/unknown disease. They are reported to be facing problem in getting education, at work place and employment, in getting married and even in acceptance in social functions. They continue to suffer stigma and discrimination which infringes on their fundamental human rights and basic freedoms and also limits their livelihood options.

According to scientific research, there are mainly seven types of albinism (Oculocutaneous Albinism; OCA1-OCA7) of which OCA3, OCA 4 and OCA 6 are found among Indian origins (Federico. et. al.,2018). Various case studies, documentaries, reports, blogs and articles on Albino people in India reiterate the fact that there is little or no awareness about albinism among common people, however, number of such reports/documents are very limited and there remains high scope for detailed study on the affected people in India which can help in constructing several social and policy measures to support this segment of our population. Albinos in India often face obstacle in leading normal life not only because of their vision

impairment but also their skin being hypersensitive to sunlight which is undoubtedly a major problem as in India people cannot escape sunlight (Jayan, 2012).

The number of people affected by albinism is reportedly increasing in India; therefore, it is necessary to conduct an all India study to assess the extent of prevalence of albinism in India and its social impact. As per RPWDs Act 2016, GOI has also included Albinism in the list of disability. The number of people affected by albinism is reportedly increasing in India; therefore, it is necessary to conduct a small study to assess the extent of prevalence of albinism in India and its social impact.

Keeping in view, Jan Vikas Samiti has initiated and entrusted White Paper Research & Analysis Pvt. Ltd. to conduct a Situation Analysis on Albinos in India with major objective to find out the ground realities and provide support to them to ensure safety, health, education, employment and non-discrimination, by educating people with facts and providing appropriate recommendation to the government to extend necessary support.

Chapter – II

Approach, Objective and Methodology

2.1 Approach:

In the background of existing cases and incidence of Albinism in various parts of India, there are a few organizations that have joined hands to support the noble cause of generating awareness on Albinism, spread knowledge on this particular genetic disorder and stand beside the Albino people do reach their voices to the society and common people. These organizations are working since past few years with Albino people to bring each possible changes in their life and living and facilitating them to gain equal rights, better opportunity, access to resources and moreover to eradicate superstition and stigma in the society about albinism.

This study is focused on developing Situation Analysis on the people with Albinism with the primary goal to review and gather information on the current situation of the Albino people in India. The policy objective of this study is to critically analyze the pros and cons of available access and facilities for the Albinos and provide recommendations based on the findings which will have far reaching impact and consequence on actions taken by policy level authorities. It is worthy to mention here that collection of primary data was a challenging task for field investigators. Approaching the Albinos for interview was not an easy and even if they agreed for the interview, it was found more difficult to make them feel comfortable to speak about their issues. During the survey, it was also felt sometimes that respondent albinos were forced to hide and under report their true condition in fear of the stigma and misbeliefs.

Therefore, this study in some cases may have some short falls in portraying the exact condition of the Albinos, but effort has been made to gain an in-depth view of the existing problems, obstacles and needs of the Albinos which will be helpful in improving their life and living condition.

2.2 Objective of the Study:

The major objective of this study is to find out the ground realities (situation analysis) and provide support to them to ensure safety, health, education, employment and non-discrimination, by educating people with facts and providing appropriate recommendation to the government to extend necessary support.

Broad objectives of the study were set to as following:

- i. To evaluate the level of awareness about albinism
- ii. To assess current health scenario of albinos
- iii. Assessment of extent of accessibility of albinos towards basic amenities and resources in the society
- iv. Assessment of social acceptability and to examine the degree of exploitation / discrimination they face, if any
- v. To evaluate the role of government and other organizations in support of albinos

2.3 Methodology:

2.3.1 Nature of study: The study used survey methods to get elicit feedback from the concerned stakeholders. Nature of survey was mix of quantitative and qualitative data collection methods. The quantitative findings have been substituted with qualitative feedback. All the selected stakeholders were personally interviewed by field investigators.

2.3.2 Data collection: Data has been collected through semi structured interview schedules with some observatory notes by the experienced field investigators. Interview schedules were

translated into English, Hindi and Bangla languages. To ensure the accuracy of data, both physical and telephonic back checks were conducted during and after the field work.

2.3.3 Selection of Respondents: Selection of respondents (albinos) for this study was indeed a challenge as there was no secondary data available on the albinos to identify their locations / residence. However, mapping could be possible with help of partner organizations of Jan Vikas Samiti working in the study areas. Availability of albinos were less in some sample states like West Bengal, Bihar and Jharkhand therefore we had to reduce sample size than proposed in these states and there was no need to use any sampling technique there, however, in Uttar Pradesh and Madhya Pradesh, random sampling technique have been used to select the respondents.

2.3.4 Sample Distribution and Geographical Coverage:

States	District	Sample Size	
		Albino	NGO Workers
Jharkhand	Ranchi	3	1
	Koderma	9	1
Bihar	West Champaran	6	2
Madhya Pradesh	Satna	4	1
	Khandwa	12	1
West Bengal	South 24 Pgns	2	0
	Kolkata	5	0
Uttar Pradesh	Sitapur	8	1
	Varanasi	9	1
	Kasganj	11	2
	Agra	2	0
	Etah	5	0
Total Sample		76	10

Table 2.1

2.3.5 Training of Field Researchers: A two day rigorous training was conducted to make the field researcher familiar with schedules for the study. Prior to training, screening exercise was undertaken to choose able field persons to conduct the study. The due weight was given to experience of field researchers in similar field. The training was divided into two parts. In first

part, all the selected field investigators were briefed about Albinism, data collection techniques and the tools to be used for data collection. In second part, mock interview was conducted to make them familiar with the survey schedule.

2.3.6 Data Analysis: The Computer software CsPro has been used for data entry. Quantified data has been analyzed using SPSS, and wherever necessary, Excel software has also been used for data analysis. Multivariate analysis has been carried out in the study. Mainly descriptive statistics have been used for analyzing sample characteristics. Prior to analysis exercise of data cleaning was carried out. Content analysis of the qualitative responses received during field work from concerned stakeholders has been carried out to ascertain the reasons.

Chapter – III

Major Findings

This section is majorly divided in to five parts:

- **Demography of the respondents (Albinos)**
- **Awareness about Albinism**
- **Social inclusion of Albinos**
- **Role of government and other organizations, and**
- **General opinion of the respondents**

3.1 Demography of the respondents (Albinos):

- **Geographical area:** Respondents for the study were selected from five states namely Madhya Pradesh, Uttar Pradesh, Bihar, Jharkhand and West Bengal.
- **Age group and gender:** Age group of the respondents ranges from 7 to 65 years, however, the mean age of sample size is 25.59 years statistically; and we have approximately 50:50 (51:49) ratio of male and female respondents in our study.
- **Marital status:** There is almost a balanced proportion of married and unmarried respondents who attends the legal age, however in Bihar, the proportion is significantly lower (1:5 for married and unmarried population).
- **Education:** Most of the respondents (more than 80%) were found to be literate however close to 17% of the total sample reportedly never went to school. It is reported that, out of total, close to half of the respondents (46.1%) have attended upto primary school education; more than 17% went to high school and 13.2% were educated upto middle school. A very few of them reported to have graduation and post-graduation degree.
- **Family income and source:** Most of the respondents (as high as 92%) reportedly belong to low income group having family income of less than one lakh per annum. While investigating on main source of family income of the respondents it was reported that

largely they were doing private job or work as daily wage labourer. A very of them reported agriculture or business as their main source of income. They are mostly involved in short-term contractual or less paid jobs indicating that they often fail to move to the high income ladder of the society to enjoy better life and living.

- **Employment status:** The employment status of the respondents seems much gloomy. Leaving apart students (31.6%) and housewives (9.2%); most of the respondents (21.6%) were reported to be unemployed, 18.4% were daily wage labourer and 10.5% were said to be part time employed. A very few of them also reported contractual or seasonal employment. Such employment status may support one of the major findings of this study that they have been discriminated by the employers in participating in usual workforce as compared to Non-Albino population and also lead to distressed financial condition.

3.2 Awareness about Albinism:

This part deals with general awareness about albinism among albinos and general public in the society. It also emphasizes on their current health scenario.

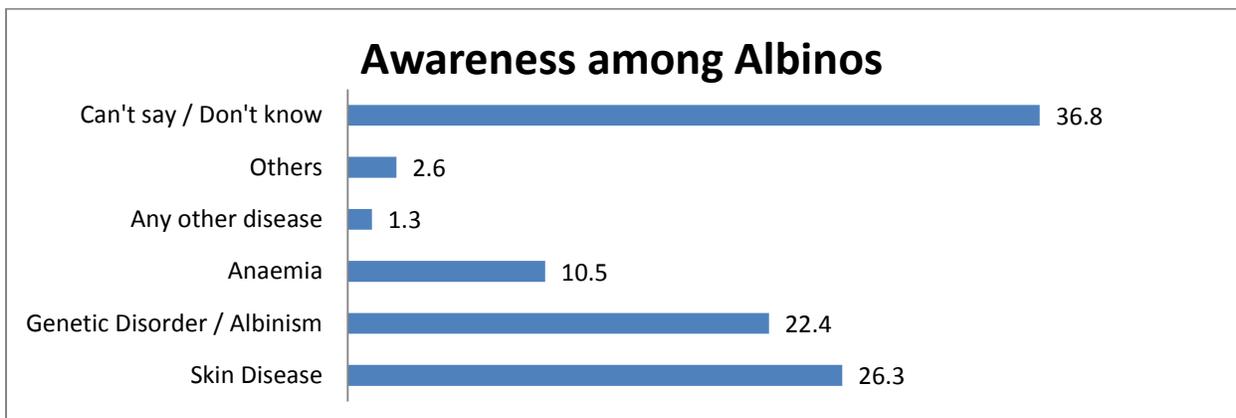


Fig. 4.1

Most of the respondents were found not aware about the reason for their different physical appearance. More than one fourth of them responded that they were having some kind of skin disease; some of them said it was due to anaemia and very few of the respondents also

reported that they might have inherited it from their father or mother who were similar to them. However, close to one fourth of the respondents were aware the fact that their different physical appearance was because of a genetic disorder or albinism.

Most of the respondents (83%) were found to be aware that their skin is hyper sensitive to direct sunlight, however, most of them reported to be not using protection always while going out in sun. Only 13.2% responded that they always use protection while going out in direct sun while 42% of them said they use protection mostly and 22% reported to have protection sometimes in direct sun light. They were not found to be aware that exposure to direct sun light may lead to skin cancer in such condition. Most of them (more than 76%), who reportedly use to protect their skin from direct sun light, responded to use of cloth to cover their skin, some of them also reported use of sun screen lotion and umbrella.

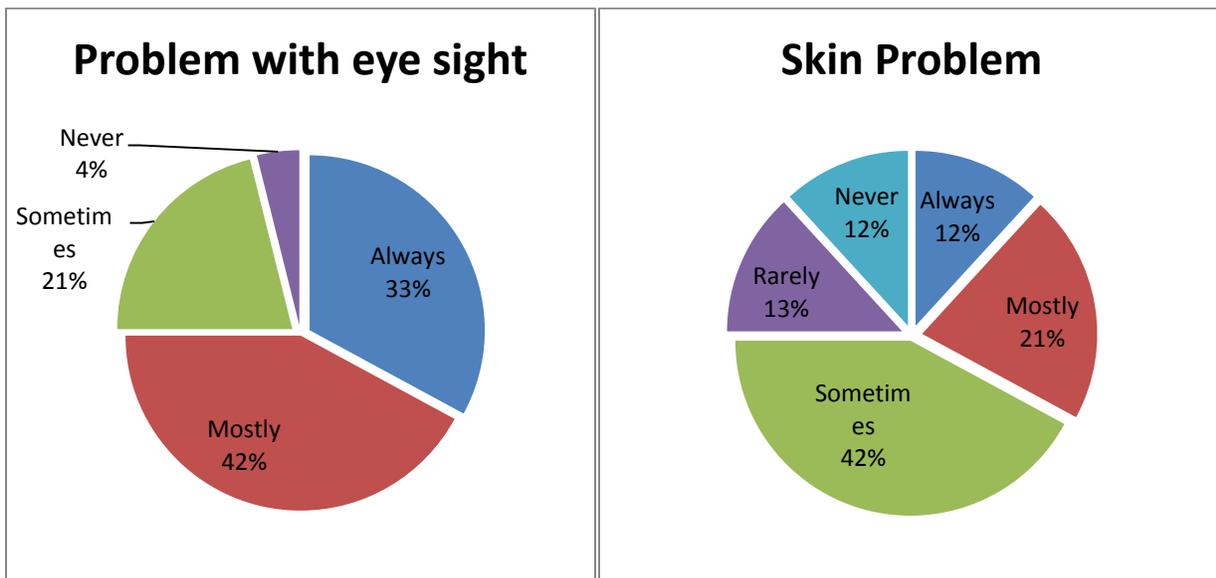


Fig. 4.2

While asking about problem with eyesight and skin, 33% of the respondents reported they always face problem with eyesight, 42% reported mostly while 21% said sometimes they face eye problem. On the other hand, 12% of the respondents reported always having skin problem

like freckles, mole spot or sun burn; 42% said sometimes they face skin related problem while some of them reported rarely or never having skin problem.

Apart from eye and skin problems, while asking about if they consider themselves to be fit and healthy to perform their daily activities, more than ninety percent (93%) of the respondents reportedly considered themselves to be fit and healthy to perform their daily activities. It was reported during the survey that close to half of the respondents never visited to doctor for regular check-up. More than two third of them reported not having any major disease during last three years, however, some of them reported viral disease, joint pain, digestive problem and other minor health issues for which they visited doctor in last three years. However, a few of the respondents, who did not consider themselves to be fit and healthy to perform their daily activities, reported that they were unable to see properly and cannot work under direct sun.

These findings establish the fact that most of the Albinos are generally fit and healthy to perform daily activities and mostly they suffer from common diseases that any normal person may have and thus should not be deprived of any opportunity and should get equal chances/right to education, employment and other basic amenities in the society.

3.3 Social inclusion of albinos:

The World Bank group defines the social inclusion as – the process of improving the terms for individuals and groups to take part in society; and the process of improving the ability, opportunity, and the dignity of those disadvantaged on the basis of their identity to take part in the society. This simply means that improvement is needed at both sides for a perfect social inclusion.

This part of the major findings of this report focuses on accessibility of the albinos to resources and amenities available in the society, their social acceptability and public behavior towards them, and some major problems they face in the society.

To understand these aspects of their life, the respondents were asked about common problems they faced during their school/college life, at work place, and at other public place due to their different physical appearance including types of such incidents and to what extent these problems have occurred in their life.

During the survey, more than 12% of the respondents reported problem faced at the time of admission in school. Most of them (44%) said that parents of other students objected for admission due to misconception that this (Albinism) could be a contagious disease; more than 37% found admission process delayed due to different physical appearance and some of the respondents also reported objection from teachers of the school.

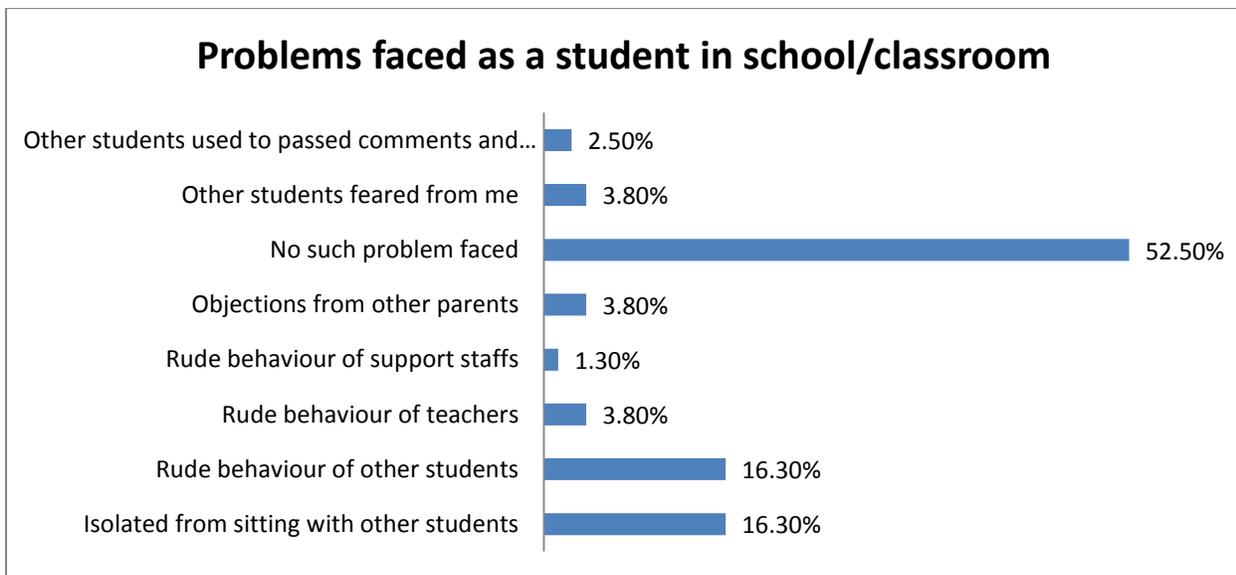


Fig. 4.3

Very few of the respondents reported drop out of the school due to albinism, however, responding to problems faced as a student during the school/college close to half of them who attended the school/college reported yes they have faced either serious or minor problems. More than 16% reported isolated sitting arrangement from other students in the classroom and rude behavior of classmates or other students in the school. Rude behavior of teachers and

other staffs have also been reported including some other problems like students used to pass comments due to their low vision and some of the other student were having some fear and they did not want to get close to them.

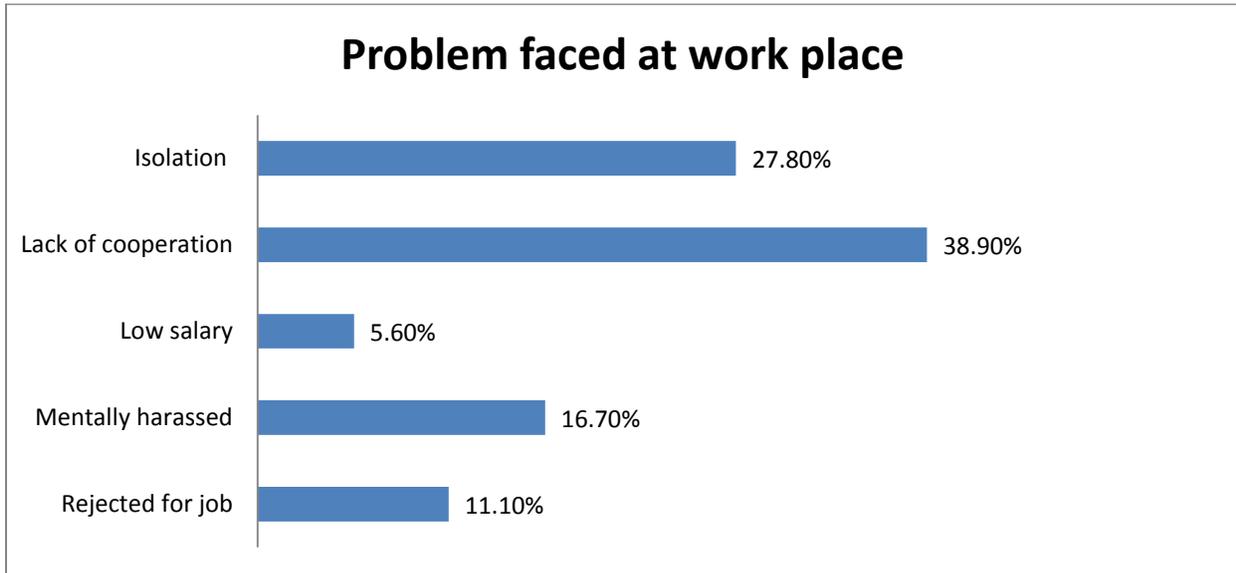


Fig.4.4

Responding to undesirable moments or problems faced at work place due to albinism, most of the respondents (52%) found to have no such problems during their job, however, some of them (12%) reported having problems sometimes whereas few of the respondents reported always having problem due to their appearance at work place. Majority of respondents (39%) reported lack of cooperation as the major problem at work place and more than one fourth found to have isolation as no one wanted to get close to them due to their different appearance. Mental harassment and rejection for job due to their condition have also been reported during the survey as some of the other major problem they used to face at work place due to albinism.

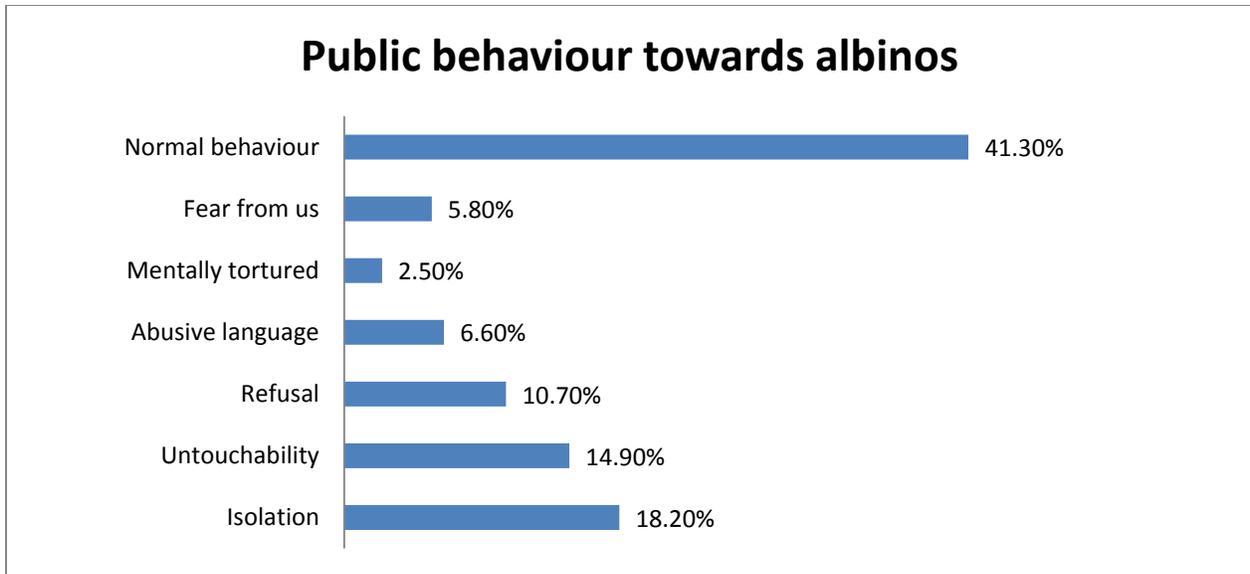


Fig.4.5

Responding to people’s behavior at public places, less than half of the respondents reported to have normal behavior of common people towards them. Most of them responded that they feel isolation, untouchability and refusal by common people at public place. According to them, common people are having misconception about their condition due to lack of awareness. Some of them also reported use of abusive language quoting the gene responsible for their condition came from foreigner and other mental harassment by public.

Responding to the question, if they have faced problems while visiting health centres, surprisingly some of them reported to have problems like unequal treatment by support staff and rude behavior by doctors and other patients. This gives a very poor picture of society where the Albinos face impolite behaviour of support staffs of the hospital and even by doctors who are supposed to have the best knowledge and awareness about their condition.

Some of the respondents reported that they were not treated equally as other non-albino person even in their own family. Main reason behind this was found to be some misbelief like it’s a disease and its infectious; it’s a curse and person in contact would get affected also. Lack of awareness can’t be ruled out for all these misbeliefs.

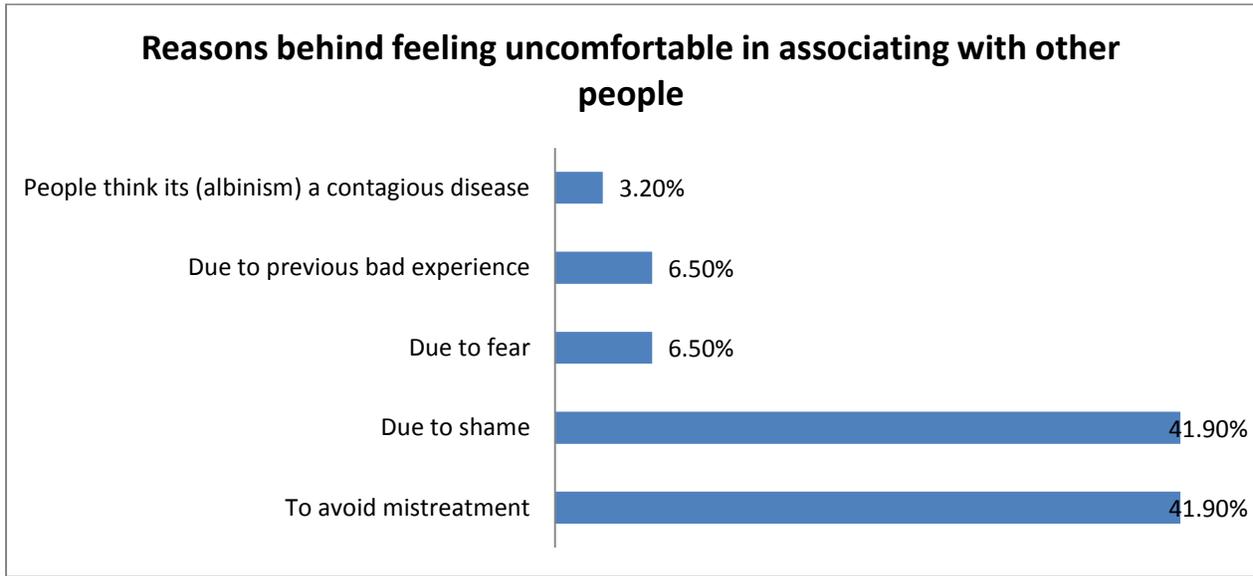


Fig. 4.6

Responding to associating with other non-albino people more than 60% of the respondents found to be comfortable whereas more than 17% of them reported not comfortable sometimes and some of them reported mostly or always having discomfort while associating with others. Main reason behind this discomfort was reported as to avoid mistreatment and due to shame. Some of the responded also reported previous bad experience and fear as their reasons to feel uncomfortable while associating with non-albino person. These findings make it apparent that there exist two ways barrier both from the society and also from the Albinos in their interaction with other people in the society.

Talking about general awareness among common people, most of the respondents (40%) opined that there is no awareness at all or very little awareness. According to the respondents, only a handful of the population have awareness about Albinism which is one of the major reason they keep on facing isolation or inequality in the society. Such troubles like feeling of isolation, refusal or poor behavior of the society drive them to certain emotional setbacks which results into fear and low confidence level. It has been reported that more than two third of respondent found to be feeling unsafe when they go out of their home. Lack of awareness

about albinism, both among albinos and non-albino common people, plays a vital role in keeping them from opportunities and equality in mainstream society.

Investigating about any major incident or undesirable experience they have faced at school or work place or any public place, most of the respondents were found to be hesitated and opt for none or refused to answer, however, most of them responded for to whom they reported such incidents. Close to half the respondents were found reported such incidents to their parents while close to one fourth of them reported to their friends or other family members. Some of them reportedly lodged complaints to local authority also but the fallacy lies in the fact that most of them found to be not aware/informed if any action was taken against the report or complaints. It can be said here that any positive action against those complaints would have been more helpful or mentally supportive for the Albinos and have helped in improving their mental strength.

These observations state that there exists an overall fear or uneasiness among the Albinos that they have high probability of facing undesirable experience outside their home premise. Though proportion may seem to be low, the psychological factors remain strong that refrains the respondents from easy and free mixing in the society.

3.4 Role of government and other organizations:

During the field survey none of the respondents was found to be aware of any government programme or scheme or facility supporting welfare of albinos. Most of them were found to be very disappointed that government is not doing anything for them.

Very few of the respondents reported presence of some non-government organizations in the study area who are providing some support to the albinos. According to the respondents these organizations are providing health related information to albinos, and generating awareness among the albinos as well as society about albinism. They are also reportedly support them accessing health facility and education, however, number of such organizations are very few

and most of the respondents were not aware about any of such organization or they were reportedly not much satisfied with their works.

3.5 General opinion of the respondents:

In this section the study tried to capture the respondent's recommendation and suggestions that could be beneficial, according to them, to improve their living condition and provide support to them in their daily life.

- Respondents (albinos) strongly believe that there should be effective government intervention and support which will help them in improving their living.
- Employment and access to health facility has been reported most importantly where they need government intervention.
- Some of them also responded that government needs to intervene in education and enforcing special provisions and facility for the people with albinism.
- Very few of them were found to be in favour of generating awareness about albinism as an area where government intervention is needed. However, responding to what steps should be taken to increase awareness about albinism; most of them opined that it should be created through local awareness camp and through media. Some of the respondent also opined that albinism should be part of the school education and hoardings containing information about albinism should be fixed at public places so that misbeliefs or wrong conceptions about the condition could be eliminated.

Here, this can be stated that even in many cases where respondents failed to be strongly vocal about on their present status and livelihood, their recommendations and suggestions reflect the fact that there are much loopholes in dealing with the Albinos in our community and that they require support or assistance in many basic areas for their survival and also for improving their current situation.

Some local NGO workers available in the study area were also interviewed to get a better understanding on current situation of albinos. Their major opinions are as follows:

- ❖ Regarding the physical condition of the Albinos, the NGO workers reported that along with eye-sight and skin problem, the Albinos are often affected with hair problems and sun burn of a higher degree.
- ❖ On availability of medical support to albinos, they reported either no medical support rarely available for treating their eye, hair and skin related problems which cause major interruption in smooth running of their daily life.
- ❖ According to them, Albinism is considered as a disease which is infectious and people are often afraid of the Albinos; and therefore in most of the cases they are treated poorly by other people in the society.
- ❖ It is more of mental abuse that the Albinos face other than physical abuse as reported by the NGO workers. According to them, irrespective of class in the society (upper, middle or lower), the Albinos face discrimination by most of the people.
- ❖ Apart from health related issues, the albinos face many other major problems in their daily life like isolation, mental abuse, discrimination and eventually unemployment and poverty.
- ❖ They have opined that government should take steps for the betterment of albinos like generating employment opportunities, support in education, provision of free health checkup and running awareness campaign in the society.
- ❖ They have also suggested that creating awareness in the society about albinism is one of the most important steps towards improving current situation of albinos so that discrimination and stigma towards albinos in the society could be eliminated.

Conclusion and Recommendation

- Extensive and exhaustive effort should be given by government, non-government and local and other authorities in creating awareness on Albinism through media coverage, newspaper promotion, social media circulation, setting up of awareness camps, promoting hoardings at public places or in schools among teachers, students and parents. The awareness programmes should also be frequent in numbers irrespective of urban or rural places and messages should be widespread that 'ALBINISM IS NOT A DISEASE, IT IS NOT INFECTIOUS AND ALBINO PEOPLE ARE EQUALLY NORMAL AS NON-ALBINOS ARE'.
- There should be adequate medical facilities provided to the Albinos specially by assisting them in term of eye-care and skin care. The Albinos could be helped to a great extent by providing free medical services like eye treatment, provision of spectacles, minor surgeries and routine eye check -up at government hospitals, PHC or by other local authorities. Similarly the Albinos should be provided with skin treatments, sunscreen lotions, medicines for skin allergies etc. at free or nominal charges at govt hospitals or medical centres. This will help the Albinos to a great extent and provide support in their daily life.
- As citizens of our country the Albinos should also enjoy right to employment as other Non-Albinos do. Thus there should be some jobs/service or work provided to the literate or educated Albino mass which requires working from inside any covered place, office or any establishment. This will help them both to protect their eye and skin and continue their job responsibilities in much hassle-free way.
- Medical awareness on Albinism must be created and spread across both Albino and Non-Albino group. The message should be well spread that the skin tone of Albinism is not curable by visiting quacks or by doing any spiritual or superstitious practices which can be both mentally and physically harmful for the Albinos. Albinism is not a disease

that can be cured and only the symptoms or health conditions can be controlled by proper medical treatment.

- There should be intervention from Govt, non-government and other organizations that can help enforcing the rights of the Albinos as other citizens avail. There is urgent requirement of establishing special schools for the Albino children where specially designed study materials and educational equipment will be provided to support their education in a smoother way.
- To promote the participation of the Albinos in all social events, there is need for organizing special counselling camps where the Albinos will be guided and taught to be more vocal about undesirable incidents that hampers their daily routine, to be more initiative and motivated in participating anywhere with the Non-Albinos and also not to feel shameful, uneasy and guilty for being an Albino. These camps would be targeted to improve the mental strength of the Albinos and to lead a normal life like other individuals.

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Appendix – I

Responses of Albinos during survey:

Gender

Male	51.3
Female	48.7

Religion

Hindu	64.5
Muslim	35.5

Cast Category

General	5.3
SC	61.8
ST	21.1
OBC	11.8

Marital Status

Married	28.9
Unmarried	69.7
Divorcee	1.3

Educational Qualification

Illiterate	17.1
Primary	46.1
Middle	13.2
High school	17.1
Graduate	3.9
Post Graduate	2.6

Employment

Full time employed	1.3
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Part time employed	10.5
Contractual	2.6
Seasonal	1.3
Daily wage earner	18.4
Housewife	9.2
Student	31.6
Unemployed	21.1
Unpaid work	1.3
Others	2.6

Average Income

Below 1 lakh	92.1
1 to3 lakh	6.6
Above 5 lakh	1.3

Awareness about their physical appearance

Skin Disease	26.3
Genetic Disorder / Albinism	22.4
Anaemia	10.5
Any other disease	1.3
Others	2.6
Can't say / Don't know	36.8

Frequency of problem with eyesight

Always	32.9
Mostly	42.1
Sometimes	21.1
Never	3.9

Having skin problems like freckles/moles or spot

Always	11.8
Mostly	21.1
Sometimes	42.1

Rarely	13.2
Never	11.8

Knowledge about hyper sensitivity of their skin to direct sunlight

Yes	82.9
No	17.1

Frequency of using protection when go outside in sun light

Always	13.2
Mostly	42.1
Sometimes	22.4
Rarely	5.3
99	17.1

Type of protection they use to protect their skin from direct sunlight

Use of sunscreen lotion	3.8%
Use of cloth to cover open parts of body	76.9%
Use of Umbrella	2.6%
99	16.7%

Visit to doctor for regular check-up

In last three months	5.3
In last six months	3.9
Last year	1.3
Before last year	21.1
Don't remember	21.1
Never	47.4

If suffered from any major disease in last three years

	Percent
No major disease	33.6%
Skin disease	15.5%
Eye disease	15.5%

Bone disease	4.5%
Mosquito borne disease	3.6%
Heart problem	.9%
Jaundice	.9%
Neuro disease	1.8%
Contamination	10.9%
Viral disease	7.3%
Joint pain	1.8%
Digestive problem	.9%
98	2.7%

Do you consider yourself to be fit and healthy to perform your daily activities apart from your difference in appearance/Albinism?

Yes	93.4
No	6.6

Reason for not considering fit and healthy to perform your daily activities

Cannot see properly / vision problem	3.9%
Always feel weakness	1.3%
Handicap / (locomotive disorder)	1.3%
Cannot work under sun / direct sunlight	2.6%
N/A	90.9%

Whether faced any problem during school/college admission due to difference in appearance

Yes	11.8
No	71.1
N/A	17.1

Major problems faced during school/college admission due to difference in appearance

	Percent
Teachers objected	18.8%
Parents of other students objected	43.8%
Admission process delayed	37.5%

Major problems face/d as a student in your school/classroom

Isolated from sitting with other students	16.3%
Rude behaviour of other students	16.3%
Rude behaviour of teachers	3.8%
Rude behaviour of support staffs	1.3%
Objections from other parents	3.8%
No such problem faced	52.5%
Other students feared from me	3.8%
Other students used to passed comments and always taunted for my low vision	2.5%

Did you ever have to drop-out of the school due to Albinism?

Yes	3.9
No	78.9
99	17.1

How often you face any problem or undesirable moments at your work place due to Albinism?

Mostly	2.6
Sometimes	11.8
Never	52.6
N/A	32.9

Major problem or undesirable moments at your work place

Rejected for job	11.1%
Mentally harassed	16.7%
Low salary	5.6%
Lack of cooperation	38.9%
Isolation	27.8%

How often do you face problem due to your different appearance while visiting hospitals/ health centres or doctors?

Always	1.3
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Mostly	2.6
Sometimes	3.9
Rarely	2.6
Never	89.5

Major problems faced while visiting hospitals / health centres / doctors

Refused services by support staff	10.0%
Rude behavior by staffs and other patients	40.0%
Not treated equally	50.0%

Did you ever feel that you are not treated equally as other non-Albino persons in your family?

Mostly	3.9
Sometimes	7.9
Rarely	10.5
Never	77.6

In your understanding why do you think you are not treated equally in your family?

They believe it (Albinism) is a disease	30.8%
They believe it is a curse	28.2%
They believe Albinism is infectious	17.9%
Due to lack of awareness	23.1%

Major type of behaviour they face mostly by common people at public places

Isolation	17.4%
Untouchability	14.9%
Refusal	10.7%
Abusive language	6.6%
Mentally tortured	2.5%
Fear from us	5.8%
Normal behavior	41.3%
They neglect us	.8%

Do you feel uncomfortable in associating with other people who are not Albinos?

Always	2.6
Mostly	9.2
Sometimes	17.1
Rarely	9.2
Never	61.8

Major reasons for feeling uncomfortable while associating with common people

To avoid mistreatment	41.9%
Due to shame	41.9%
Due to fear	6.5%
Due to previous bad experience	6.5%
People think its (albinism) a contagious disease	3.2%

How would you rank the general awareness of the common people about Albinism?

Extremely aware	1.3
Aware	4.0
Somewhat aware	37.3
Hardly aware	16.0
Not aware at all	40.0
Can't say	1.3
Total	100.0

How often do you feel unsafe when you are outside your house/shelter?

Always	5.3
Mostly	7.9
Sometimes	21.1
Never	65.8
Total	100.0

Please tell us about any undesirable experience you had in school due to Albinism

None	79.7
Did not answer / refuse to answer	7.2
Teasing and mimic by other students	1.4

No one wanted to be friend / classmates maintained a distance / feeling of isolation / they ran away from me	1.4
Rude behavior by mates and physical harassment	1.4
N/A	8.7

Please tell us about any undesirable experience you had at your workplace due to Albinism

None	59.4
Did not answer / refuse to answer	5.8
People kept a distance from us / feeling of untouchability	2.9
N/A	31.9

Please tell us about any undesirable experience you had at any public place due to Albinism

None	88.4
No comments	8.7
Skirmish due to abusive language	2.9

If you ever experienced any undesirable incident due to your different appearance (Albinism), to whom did you report?

Parents	40.0%
Friends	24.0%
Other family members	24.0%
Local authority / head	8.0%
Teacher	4.0%

Do you know whether your complaint was noticed and action taken on?

Yes	1.3
No	12.0
Don't know	5.3
N/A	81.3

Are you aware of any government facilities/scheme/programme for the people with Albinism?

No	100.0
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Is there any non-government or other similar organizations in your locality which provides help and support to the Albino people?

Yes	9.2
No	60.5
Don't know	30.3

If yes, what are the areas these NGOs provide support to Albino people?

Generating awareness on Albinism	22.2%
Providing health related information to Albino people	55.6%
Supports in medical treatment	11.1%
Supports in education	11.1%

How much you are satisfied with the support provided by the NGOs or similar organization?

Satisfied	1.4
Moderately satisfied	8.7
Dissatisfied	2.9
N/A	87.0

Major areas they need government intervention to improve your well-being

Education	16.1%
Health	24.4%
Employment	28.9%
Public transport	8.9%
Enforcing special provisions and facilities for people with Albinism	12.8%
Improve public awareness	8.9%

In your opinion what steps should be taken by the government to increase awareness on Albinism

Media coverage	24.6%
Local awareness camps	34.3%
Newspaper promotion	17.7%
Hoardings at public palces and road sides	10.3%

Albinism should be part of school syllabus	10.9%
Awareness camp at health centre	.6%
It should be discussed in regular meeting at school among parents and teachers	.6%
Work on community awareness	.6%
No expectation from govt. or NGOs	.6%

Any other suggestion you would like to say for improving the life and livelihood of the Albino people?

Need govt job	6.7%
Need office job which doesn't require to go out in sun	41.1%
Free education	4.4%
Free skill development training	14.4%
Provision of pension	10.0%
Free health check up	6.7%
Create awareness among public	3.3%
No comments / can't say	13.3%

Appendix – II

Photo Album:





Albinism in India: A Situation Analysis

